390 Mentoring people with cystic fibrosis: evaluation of the preparation and process

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Background: The benefit of mentoring in chronic disease management is increasingly recognised.
Aim: To evaluate preparatory training, delivery and impact on work practices of telephone-delivered self-management support augmented by information technology (IT) tools for people with cystic fibrosis (CF).
Method: Volunteer health professionals undertook 12 hours of training covering CF, health-mentoring, and IT tools: a database and a mobile phone programme with symptom-monitoring through daily text messages. Health-mentoring was incorporated into daily workloads over six months. Understanding of mentoring, self-management, self-efficacy, goal setting, action planning and mentoring self-efficacy were measured pre/post training on a five-point Likert scale by self-administered questionnaires. Qualitative data were collected by self-report, focus groups and interviews.
Results: 29 of 34 mentors completed the training, which met the needs of 78.6% (22/29). Pre and post there were significant improvements in understanding of mentoring ($p < 0.001$), self-management ($p = 0.002$), self-efficacy ($p < 0.001$), action planning ($p = 0.001$) and mentoring self-efficacy ($p = 0.006$). Via in-depth qualitative interviews, mentors reported translating acquired skills to other work areas. Challenges included communication by phone, and closure of the mentoring relationship.
Conclusion: Mentor training can alter health professionals' understanding and practices, particularly when incorporated into teams where there will be a mid- to long-term relationship.

391 Education and CF: experiences of parents and schools

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Aim: The University Hospital of Leuven's CF team and hospital school investigated how they, parents and home schools work together to provide schooling to patients.
Method: Parents and home schools of hospitalized children were asked to complete a questionnaire from their perspectives, covering information the home school received about CF, communication with peers, allowances made for CF in home schools, etc.
Results: 22 children were hospitalized during the school year 2007–2008. Nine children attended hospital school: parents and home schools of 8 patients consented to the study. Parents were home schools' main source of information about CF (using leaflets from the patient association). Information included: details about CF, hygiene, nutrition, absence, etc. Seven schools informed classmates about CF; this was done by the child and/or a teacher or parents. Neither parents nor schools reported bullying. Special allowances were made by 7 schools, such as using two sets of books, copying notes during absences, extra help with exams, help with medication, rules about hygiene, home tuition, etc. All home schools had been in contact with the hospital school, e.g. to discuss the content of courses, exams or behavioral issues. These contacts were considered vital to optimize care and education, improve re-integration after hospitalization, help with future choices, etc.
Conclusion: Regular contacts between parents and home/hospital schools take place and are considered important. Schools make allowances for children with CF, but to do so they need information about medical and practical issues. These preliminary results show that communication is essential to help the child, parents and school cope with CF at school.
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392 A way in therapeutic education (TE) for the children with cystic fibrosis and their family

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Introduction: CF is a severe chronic illness and health care professionals have to propose therapeutic education, helping parents and patients to "live with the disease".
Method: our CF centre proposes an approach of TE for the children and their family since the diagnosis (by neonatal screening) at about 1 month-of age to transition from paediatric to adult care. The first meeting concerns parents of children before two years of age, in order to get to know each other, with all the team present as well as an adult with cystic fibrosis and 2 parents of older children. Others meetings are then organized by our psychologist to these new parents, to express themselves on the disease. Then, for parents of 2–3 years old children, 4 collective sessions are proposed over a year, to improve skills about most important objectives: respiratory and nutritional. Each child personal physiotherapist is invited to participate. A few years later, children 5–6 years old, 10–11years old, and 15–18 years old are invited with their parents: 4 afternoons over a year, that are centred on their specific learning needs. First afternoon: an educational need assessment helps to set up "relevant objectives". Second and third afternoons: relevant objectives are studied by both participants in each group with interactive and playing tools. Fourth afternoon is focused on skills acquired. Hygiene precautions are respected to avoid across infection. Activities like: "how to resolve problems and situations" are proposed. Individuals learning activities are planed during consultations.
Conclusion: families appreciate this TE approach. It helps medical team to prove objectives results on patient's health and quality of life. Skills on self-management and anticipation are therefore increased.

393 Creating a CF community – 'CF in the City' – a CF Newsletter

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130 young people from the East Midlands visit Nottingham University Hospital for their CF care on reaching adulthood. In a large geographical area patients often have to travel long distances to the specialist hospital. They also break their long established contact with their local health facility. These factors, as well as limited knowledge of the condition and problems with peer support (due to infection control), can increase the young adults' feelings of isolation.
With these factors in mind we established a newsletter. It aims to assist patients to feel part of 'the CF community', and to provide useful information. Not all patients have access to the Internet and some are fearful of looking for CF related information where denial is part of their coping strategy. A paper copy of the newsletter is sent by post to all adult patients unless they indicate that they do not want to receive it.
'CF in the City' has been circulated to patients involved in Adult CF Services at Nottingham for the past two years. Approximately 160 copies are now sent out quarterly – staff involved in CF also receive a copy. Typically the newsletter contains information about the service, a benefits article, an editorial featuring a current issue, and at least one article by a CF patient/service user. As readers become more familiar with the newsletter, more patients have been in contact to propose articles. It is also hoped that the newsletter will encourage service users to provide feedback about the service generally. Comments have been positive and there will be further research on what patients find most valuable. The CF adult and paediatric teams are now also discussing the possibility of a joint newsletter to be circulated to all patients in the region.